North Tyneside Council Report to Cabinet Date: 13 November 2017

ITEM 6(h)

Title: Adoption of the Motor Neuron Disease

Charter

Portfolio(s): Adult Social Care Cabine

Cabinet Member(s): Councillor Gary Bell

Report from Service

Area: Health, Education, Care and Safeguarding

Responsible Officer: Jacqui Old, Head of Health, Education, (Tel: (0191)

Care and Safeguarding 6437317)

Wards affected: All

PART 1

1.1 Executive Summary:

To seek Cabinet's approval to adopt the Motor Neuron Disease (MND) Charter, which sets out the care and support that people living with MND and their carers deserve and should expect.

1.2 Recommendation(s):

It is recommended that Cabinet:

- (1) adopt the Motor Neuron Disease (MND) Charter; and
- (2) approve the plan for promoting the Charter within the Borough as set out in Section 1.5.9 of the report.

1.3 Forward Plan:

Twenty eight days notice of this report has been given and it first appeared on the Forward Plan that was published on 16 October 2017.

1.4 Council Plan and Policy Framework

This report relates to the following priorities in the Our North Tyneside Plan

For People to be:

- Healthy and well with the information, skills and opportunities to maintain and improve their health, wellbeing and independence
- Be cared for and safeguarded if they become vulnerable

1.5 Information:

1.5.1 **Background**

1.5.2 This report is submitted to Cabinet in accordance with the following Motion that was unanimously supported by Full Council at its meeting held on 28 September 2017:

"MND Charter

This Council recognises that, whilst it is Northumbria Health Care Trust that commissions support for people with neurological conditions, including Motor Neurone Disease (MND), many decisions about services used by residents with MND, such as social care, housing adaptations and support for carers, are made here at local authority level.

This Council therefore requests Cabinet to consider the adoption of the Motor Neuron Disease (MND) Charter, which sets out the care and support that people living with MND and their carers deserve and should expect.

Cabinet is also requested to promote the Charter within the borough and make it available to all councillors, council staff, partner organisations and health and social care professionals who deliver services for the Council. This will serve to raise awareness of MND and demonstrate what good care looks like for those living with this devastating disease. It will also assist the Council, working closely with Northumbria Health Care Trust to positively influence the quality of life for local people with MND and their carers living in our community.

The MND charter is a statement of respect care and support that people living with MND and their carers deserve and should expect:

- The right to an early diagnosis and information.
- The right to access quality care and treatments.
- The right to be treated as individuals and with dignity and respect.
- The right to maximise their quality of life.
- Carers of people with MND have the right to be valued, respected, listened to and well-supported."
- 1.5.3 Motor neurone disease (MND) is a neurodegenerative disease that causes rapidly progressive muscle weakness. Specifically, the disease affects nerve cells (motor neurons) that control the muscles that enable you to move, speak, breathe and swallow.
- 1.5.4 MND is also known as Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease. MND typically affects people in their mid-50s and survival is approximately 2-5 years from the onset of symptoms. Although there is currently no cure for MND, an antiglutamatergic medication is available and slows the progression of the disease.
- 1.5.5 The incidence rate of people who will develop MND each year is about two people in every 100,000.
- 1.5.6 It is acknowledged that many of the aspects of this charter relate to an individual's health needs; however there are social care aspects of an individual's life that could require involvement from the Authority.
- 1.5.7 In determining the level of involvement the Authority will assess need and exercise its duties in accordance with the requirements of the Care Act 2014. That could mean

providing advice, information, signposting or support (which would be financially assessed regarding an individual's contributions).

1.5.8 Plan for Promoting the Charter in the Borough

- 1.5.9 The plan for promoting the charter would include:
 - Sharing with all relevant Authority staff;
 - Publicising the charter through various publications for example TeamWork (for staff), the Our North Tyneside Magazine (for residents of the Borough); and
 - Promoting the Charter through the Authority's website and the use of social media.

1.6 Decision options:

The following decision options are available for consideration by Cabinet

Option 1

To adopt the Charter and to ensure it is promoted across the borough of North Tyneside.

Option 2

Not to adopt the Charter.

Option 1 is the recommended option.

1.7 Reasons for recommended option:

Option 1 is recommended as it will support increased awareness of MND across North Tyneside and will demonstrate a commitment by the Authority to support people with this disease.

1.8 Appendices:

None

1.9 Contact officers:

Alison Tombs, Assistant Director Wellbeing and Assessment, Adult Social care, tel. (0191) 643 5963

Alison Campbell, Senior Business Partner, tel. (0191) 643 7038

1.10 Background information:

The following background papers/information have been used in the compilation of this report and are available at the office of the author:

- (1) Motor Neuron Disease Association website https://www.mndassociation.org/about-mnd/where-do-i-start/what-is-mnd/
- (2) Motion to Council on 28 September 2017 (text of motion is set out in Section 1.5.2 above).

PART 2 - COMPLIANCE WITH PRINCIPLES OF DECISION MAKING

2.1 Finance and other resources

In adopting this charter there are no financial implications over and above existing legislative duties.

There will be no additional cost for promoting the charter, as it will be included in existing publications and communications

2.2 Legal

In relation to Adult Social care the Authority has a duty under the Care Act 2014 to assess an individual regarding their "eligible needs," subject to a financial assessment.

The Care Act 2014 also requires the Authority to provide support to carers.

There are no other legal implications for the Authority in addition to the duties required by the Care Act 2014.

2.3 Consultation/community engagement

2.3.1 Internal Consultation

Cabinet is requested to consider the adoption of the Motor Neuron Disease Charter following Full Council's approval of a Motion at its meeting held on 28 September 2017.

2.3.2 External Consultation/Engagement

Subject to Cabinet approval, the Charter will be promoted to all Councillors, all Authority staff, partner organisations and health and social care professionals who deliver services for the Authority.

2.4 Human rights

The Charter supports the Authority duty in promoting Human Rights for people with MND.

2.5 Equalities and diversity

The Charter supports the Authority duties in promoting equality for people with MND.

2.6 Risk management

There are no risk management implications arising from this report.

2.7 Crime and disorder

There are no crime and disorder implications arising from this report.

2.8 Environment and sustainability

There are no environment and sustainability implications arising from this report.

PART 3 - SIGN OFF

 Deputy Chief Executive 	Х
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- Head(s) of Service
 X
- Mayor/Cabinet Member(s)

 X
- Chief Finance Officer X
- Monitoring Officer
 X
- Head of Corporate Strategy
 X